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Nourishment and the Ethics of Lament

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Introduction

The work of the National Conference of Catholic Bishops, the Bishops' Committee for Pro-Life Activities, and Joseph Cardinal Bernardin in promoting a fuller public discussion of medical issues pertaining to the elective use of life-sustaining treatments has been insightful, nuanced, and constructive. I join you in this discussion as a friend and as a colleague in your concern for the practice of health care to explore with you the debate about the elective discontinuation of nourishment. Within medical ethics, this debate is especially complex and challenging. Conventional wisdom holds that this debate is simply about whether the decision-making principles developed for evaluating life-sustaining technologies may be extended to tube feedings. Critics, of whom I am one, while accepting that there are circumstances when tube feedings are not obligatory, wonder whether equating nourishment with other medical treatment is either necessary, sufficient, or wise.

As we debate the adequacy of the nourishment as treatment equation, we must keep in mind that the public discussion of the elective provision or withholding of nourishment is heard by two audiences: public policy and private hearts. In public policy, this debate addresses the concerns of institutions and professional groups. This is a debate about the public conduct of institutions. When dying occurs at home, sips of broth lovingly tendered by family caregivers to the limit of satiety fulfill the moral obligation to feed and to care. Today, when 80 percent of deaths are in institutions, the recognized physiologic inadequacy of these same sips of broth provoke a moral crisis about the conduct of public life. Can food for the vulnerable and voiceless who are dependent on our institutions be elective? This question and our discomfort with our own judgment is magnified by the immense costs of

sustaining such persons. This debate is heard in the private hearts of families, patients, and health care practitioners at an hour of medical catastrophe where the foundations of interpersonal faithfulness are re-examined, tested, and hopefully learned anew.

A New Policy Solution

The current resolution to the question of whether food and water are elective is the proposal that nourishment simply be considered as a medical treatment. As such, nourishment is elective and may be withdrawn if it does not serve the patient's interests or preference. It is important to note that the equation of nourishment with medical treatment is not an ancient truth, but is a newly minted social policy designed to permit the discontinuation of nourishment under certain circumstances. This solution is recent: created, articulated, and endorsed by a President's Commission, the American Medical Association, and several courts over just the last five years.

The success of this equation in permitting nourishment to be discontinued under extreme circumstances, mainly coma and endstage dementia, has muted criticism of the limitations and dangers of this artifice. In the Raquenna and Jobes decisions, courts have dispensed with the objections of nurses or sectarian health care facilities which dissent from this equation. The potential for this new equation to undermine the entitlement to food for vulnerable persons has been only cursorily examined. The possible usefulness of alternative understandings of the problem of nourishment have generated little interest.

Three Vignettes

I would propose that the debate about elective nourishment should be more fundamentally examined at the level of the definition of nourishment. I would like to explore this question through three vignettes which, to my mind, illuminate the importance of this perspective.

* A short time ago, I visited a public long term care hospital for the chronically mentally ill to do a series of lectures on geriatric medicine. During a tour of the facility, the medical director asked me if I would like to see the "feeding ward". I assented and we went to a back ward area consisting of two rooms with nine beds against two walls, 18 beds per room, 36 for the ward. On each bed was a lump, entirely covered by a blanket. At the head of the bed was a pump on a pole from which a tube ran under the blanket. A single nurse serviced 18 patients; she sat at a small desk in the corner of the room. The ward was still. The medical director, a man about 50, told me with some pride that he had created a new life form. "I call them 'gerons'," he said. I asked him if any of the patients had been involved in the decisions leading to this kind of support. He said, "No, by the time they reach the stage where the tube is placed, they have long since been unable to participate in their care." I asked if the families attended

these people. "No," he said, "families get quite discouraged by this kind of situation and stop coming." I asked if there was any ongoing review of whether this type of care should continue. He said, "Oh, no, that would be unthinkable."

What is this nurse to these patients, without family, without advocates, a caregiver surrogate for society's respect for the vulnerable or a biotechnician serving fragile bio-mechanical systems? Is this automated feeding ward an expression of ethical commitment or the result of an ethical paralysis?

* A 65-year old man was dying of disseminated colon cancer. He was cared for by his wife, a wonderful Australian nurse, a joyous, forthright woman. We had many times discussed the coming end of his life; he was beyond chemotherapy and had rejected resuscitation and other life-sustaining therapies. Shortly before going home, he had however, taken a transfusion for extra strength to attend his son's wedding. While at home on a home hospice program, he slipped and broke his leg from a cancerous bone deposit. He was admitted to the hospital. During the last six weeks of his life, all he could take was fluids which were conveyed by the hand of his wife. In the hospital, he passed into a coma and appeared insensate to suffering. His wife came to me, acknowledging that he was dying, acknowledging that fluids could not sustain his life, acknowledging that he probably could not feel thirst, and yet still requested an IV so that the fluids might continue. An IV was placed and he died a day or so later.

Was this IV a pointless invasion of a dying man which in no way served an identifiable medical interest? Probably. But is this IV better seen as a response which recognized that the offering and partaking of fluids over the preceding six weeks of his dying had acquired a vital symbolic meaning of a nurturing, faithful relationship? Would he not have altruistically consented to his wife's request? I thought so.

* A woman was dying of breast cancer in a home hospice program. Her family had been lovingly involved in her care. As not infrequently happens, she passed into a coma shortly before her death and her final hours were distressing to the family who readmitted her to a hospital. Observing the care plan of this dying and unconscious woman, the dietitian did not order meals. The family expressed discomfort over this lack of feeding. Meal trays were ordered, brought to the bedside stand where they stood as a mealtime offering for a suitable interval before they were removed, uneaten.

Is this just a silly piece of magic? Or, is this uneaten tray at the bedside an element in a profoundly important, deeply moving, family ritual, (like the last rites, which themselves involve food) in which a family expresses its continued faithfulness to the humanity and importance of a dying loved one?

These three cases challenge both reason and feeling. What is it about the perfectly administered, physiologically sound nourishment of the feeding ward that strikes us as such a grotesque caricature of feeding? And, what

is it about the simple presence of the uneaten tray at the bedside that strikes us as absurd but profoundly definitive of the essence of nourishing? I believe that the answer to these questions lies in the communitarian context of nourishment, an aspect which I would now briefly explore.

Feeding and Alimentation

Nourishment is a transaction between two parties. I feed you, you take food from me.¹ As a transaction, nourishing is composed of a spectrum of actions: offering food, encouraging a person to eat, seeing that sufficient food is available to relieve hunger and thirst, and finally sustaining life. These acts are morally distinct. Even if it were decided that it is improper to delay death, it might still be proper to offer food, to encourage one to partake of it, or to relieve hunger or thirst.

Caregivers and patients approach this transaction from different sides and thus bear different moral responsibilities and moral authority for the various nourishing actions. Even if we grant that a patient has primary authority for evaluating life-sustaining nourishment, the patient's preferences in this matter may not void a caregiver's duty to offer food, to make food available, or to see that hunger or thirst are relieved. Resolution of who has the greater authority in disputes is more complex than whether we are speaking of the giving (caregiver's) or taking (patient's) side of the transaction. For underlying this transaction is the fact that patients and caregivers may be engaging in two fundamentally different kinds of interactions which take place simultaneously. I call these interactions "alimentation" and "feeding."

Nourishment may be "alimentation," a medical operation intended to achieve physiologic objectives and enforced by medical monitoring. As a physiologic intervention, alimentation belongs to the ethics of elective medical treatments. It may be excessively burdensome or futile as a technique or in relation to unobtainable ends. Individuals, sometimes through intimate surrogates who speak on their behalf, are responsible for evaluating and consent to this invasion.

Nourishment is also an act of caregiving that I call "feeding." Feeding is morally defined in a broader, non-medical, cultural experience. In our daily lives, feeding is an integral part of sharing the experience of human passage. Consider the full associations of breast-feeding, wedding feasts, the food brought to the bereaved. (I must say that if a medical student ever claimed that breast-feeding was simply an inter-organismal transfer of an aqueous-colloid solution, I would greatly fear that he had been irreparably damaged by too much education.) Feeding is also an expression of our vital interdependence on one another, as it is celebrated in Thanksgiving and potluck. Finally, in the Seder or the Eucharist, the shared meal is the most perfect image of moral relationship: shared, life-sustaining, peaceful, and holy.

The ethic of feeding is quite unlike the ethic of treatments. Feeding is not

about physiologic ends — it is about faithfulness. Thus, decisions about feeding rest on an interpersonal, communal foundation. We need a different, non-physiologic medical ethic to fully address the problem of feeding. A foundation for this ethic is suggested by the origins of the word “care.” The word “care” is not related to the Latin “caritas” or charity; it is of Germanic origin: the word “chara” means “lament.” An “ethic of lament” is quite unlike an ethic of treatment. It juxtaposes love for a human life with a recognition of mortality. It is fundamentally interpersonal, mediated through common symbols and usages. In lament for the irreversibly ill, problems of caring for a body are examined in light of the duties of faithfulness and the integrity of caregivers. The duties of lament require a steadfast presence and a letting go which can well accommodate the full range of options for nourishment. This is quite unlike a medical ethic where the duties of faithfulness are defined by the possibilities of physiology.

Public Policy and Private Lives

A public resolution of the tensions posed by feeding and alimentation will be very difficult. The position that nourishment is simply a medical treatment is a shallow, one-sided artifice that was designed to permit the discontinuation of nourishment. This medicalized view does not adequately protect the entitlement to food for disabled persons. It is not adequate for understanding the complex reactions of families and some health professionals to this issue. Insisting that nourishment is a treatment persuades us to do violence to families who would feed, suggesting that their quest to be faithful should be voided as a psychological problem motivated by irrational denial, magical thinking, or a wish to be destructive of a patient's autonomy. Likewise, the position that nourishment is the essence of keeping faith with the vulnerable is unbalanced. It suggests a public policy that would mandate nourishment. Divorced from loving and individualized judgments, it leads us straight to the feeding ward.

Modernized nourishment technology is advanced to the degree that we must exercise discretion in its use. Thus, the issue of elective nourishment is not a place to make the fundamental stand against medical killing even though the routine cessation of life-sustaining nourishment could easily become a *de facto* form of euthanasia for the vulnerable. Unfortunately, the distinction between withholding nourishment on the morally unacceptable judgment that a person is not worthy of life and between the sometimes appropriate conclusion that continued alimentation is an unconsented to and burdensome invasion is a distinction which exists in the hearts of those involved. The act of withholding nourishment does not reveal the heart's intent. The elusiveness and importance of this distinction is the heart of the statement signed by many prominent ethicists, theologians, and physicians which I was honored to sign.²

We return to the two discussions about elective nourishment — to

public policy and private hearts. Public policy is a crude instrument which should affirm important values as it accommodates with nuanced and flexible wisdom, the surprising individuality of human problems. Public policy for health care institutions must come to some kind of accommodation with elective alimentation, one that does not do violence to the family claim to feed. In doing so, a medical ethic will have to strive for a broader more inclusive accommodation with the symbolic language of families than has been possible with the "patient autonomy and best interests" language we now employ.³ Public policy will need to provide much better protections for vulnerable persons — not just ombudsman, but more sensitively trained health care providers as well.

In the realm of the heart, at the time of medical catastrophe, intense emotions of love and loss and fear can cause moral confusion and impulsive action. Pastoral guidance for distressed family and professional caregivers is urgently needed: guidance, not judgment. The secrets of the heart's intention and of the measure of its remorse at the loss of what is precious will guard many of these decisions from our verdict.

References

1. I have examined this issue more fully in Miles SH. "Futile Feeding at the End of Life: Family Virtues and Treatment Decisions". *J Theoretical Med* 1987;8:293-302.
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 3. National Conference of Catholic Bishops, Committee on Pro-life Activities. Statement on the Uniform Rights of the Terminally Ill Act. July, 1986.
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